PUBLIC PRIVATE PARTNERSHIP AND HEALTH SERVICE DELIVERY IN UGANDA. A CASE OF BUGIRI DISTRICT

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DECLARATION

I do hereby declare that this dissertation presented is my own work and it has never been presented to any academic institution for any academic qualification. This dissertation may be produced, stored in a data base or retrieved system, or retransmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise without the prior written permission from the authors.

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Signature.....

Date.....20/02/2014.....

APPROVAL

This is to confirm that the researcher's work has been done under my supervision and subsequently approved by me.

Supervisor

Signature.....

Date. 20/02/2014 .....

DEDICATION

I dedicate this research work to my parents who have understood during my study of social work and my friends for their support.

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ACRONYMS

ACP.....AIDS Control Program
AIC.....AIDS Information Centre
BI.....Bamako Initiative
DMO.....District Medical Officer
HUMC.....Health Unit Management Committee
LC.....Local Council
NGO.....Non-Governmental Organisation
NRM.....National Resistance Movement
PAC.....Parish AIDS Committee
PWA.....Person with AIDS
PWHIV.....Person with HIV
TASO.....The AIDS Support Organisation
TB.....Tuberculosis
SAPs.....Structural Adjustment Programs

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CHAPTER ONE
INTRODUCTION

1.1 Introduction

The first cases of HIV/AIDS in Bugiri district appeared in the early 80s, although the local population did not understand what it was like, most people perceived the problem as witchcraft

1.2 Study Background

Since the mid-1980s most developing countries have embraced Structural Adjustment Program (SAPs) imposed by the World Bank and the International Monetary Fund (IMF) aiming at correcting distortions in the economies. Uganda in particular has been implementing SAPs since 1987, aimed at restoring economic stability. SAPs stress increased reliance on market forces and the private market, with a concomitant withdrawal of the state from resource allocation especially for the social sector. In relation to health as one of the components of the social sector, the World Bank has been encouraging countries in the developing world to introduce, and increase user-fees which are charges levied on a patient for treatment of an illness. It is within this context that the government of Uganda encouraged a user-fees initiative.

Under legal Notice 1 of 1987, the National Resistance Movement (NRM) government appointed a Health Policy Review Commission to "review, examine and inquire into the Health System and Policy". The Commission recommended, among others, the introduction of user-fees in all government health units as one of the possible alternatives for generating additional funds for health to address the on-going deterioration of the health services. This is in line with the Bamako Initiative (BI) launched in September 1987 as a means of increasing access to essential drugs through community participation and revolving drug funds. The recommendation of the Commission is accepted by government in the White Paper, but before the policy could be implemented government decided to postpone it and instead considered the taxation option.

Ever since HIV/AIDS is first recognised in Uganda in 1982 in Bugiri district, it has become a major health problem emerging as the leading cause of death among Ugandan adults. More than 1.5 million Ugandans (10% of the total population and 20% of sexually active men and women) are estimated to be infected with HIV, a virus that causes AIDS (STD/ACP, 1995). Since 1982 a cumulative total of 48,312 AIDS cases in Uganda had been reported to the STD/ACP Surveillance Unit by the end of December 1995 (STD/ACP). Of these, 92.2 percent are adults

aged 12 years and above with the diagnosis, these figures represent only a small fraction of the actual number of people infected with HIV/AIDS.

1.3 Statement of the Problem

The problems associated with declining public expenditure provision have been made worse by other aspects of Structural Adjustment Programs (SAPs), including recourse to user-fees to finance health services. This is occurring in Uganda amidst the impact of HIV/AIDS which, among others, has exacerbated the health needs of AIDS affected households. Although people with terminal illnesses will be officially exempted from paying user-fees, the exemption system does not cover the entire family. In situations where the AIDS patient happens to be the breadwinner to the family, such a family could experience several needs. Besides the official protection of the person with AIDS, the exemption systems will be also designed to shield the poorest from payments, but the absence of institutional capacity has rendered these systems inadequate.

All the above could imply an increase in health care expenditures when budgets of AIDS affected households will be getting squeezed, suggesting that increasingly hard choices might have to be made among competitive demands. The end result could be those AIDS patients' health needs and those of other household members will inadequately be met, reflecting a phenomenon of inequity of access to health services for such households.

1.4 Purpose of the study

To assess the impact of user-fees on access to health services for rural households affected by AIDS, and how they cope with health care costs as compared to non-AIDS affected households in the same locality.

1.5 Objectives of the study

i. To assess the health care needs of households affected by AIDS compared to non-affected households in same community.
ii. To examine the impact of user-fees on health seeking behaviour of the rural households affected by the AIDS epidemic.
iii. To establish AIDS affected households and the non-affected cope with health care costs/burdens in light of user-fees.

1.6 Research questions

i. What health care needs for rural households affected by HIV/AIDS as compared to non-affected households?
ii. What are the perceptions, knowledge and attitudes about user-fees for health services?
iii. How do user-fees impact on health seeking behaviour of HIV/AIDS affected households in rural Nabukosi sub-county in Bugiri district?

1.7 Scope of the Study

The study focused on assessing; the impact of user-fees on equity of access to health services in AIDS affected households in rural areas in Bugiri district, which comprises of the parishes of Kapyanga, Muterere and Ndifakulya

1.7.1Time scope:

The research was carried out for the period covering from the year 2011. This time period was chosen because the consistent decline in its performance started around this time.

1.7.2 Content scope:

Content scope based on the impact of user-fees on equity of access to health services in AIDS affected households in rural areas.

1.7.3 Geographical Scope:

This research was carried out in the parishes of Kapyanga, Muterere and Naluwerere in Nabukosi sub-county of Bugiri district.

1.8 Significance of the Study

i. Policy makers such as government can use the findings of this research to come up with good policies concerning the user-fees on equity of access to health services in aids affected households in rural areas.
ii. The selected case study: help it to come up with a system that is accessible and flexible and also improve on the one in existence.
iii. This study shall be used as a requirement for the award of a degree of bachelors of Development studies of Kampala International University.
iv. Future researchers shall use the findings got from this research as future references as they do their research in the topic and also related topics.

1.9 Conceptual Framework

This study is conceived within the interactional frame of reference that forms the safety-net within which AIDS affected households and non-affected households, and individuals live, and the social dynamics underlying health seeking behaviour and the ability and willingness to pay for health services.

Conceptual Framework: Impact of User-Fee on Access to Health Services in AIDS Affected Households

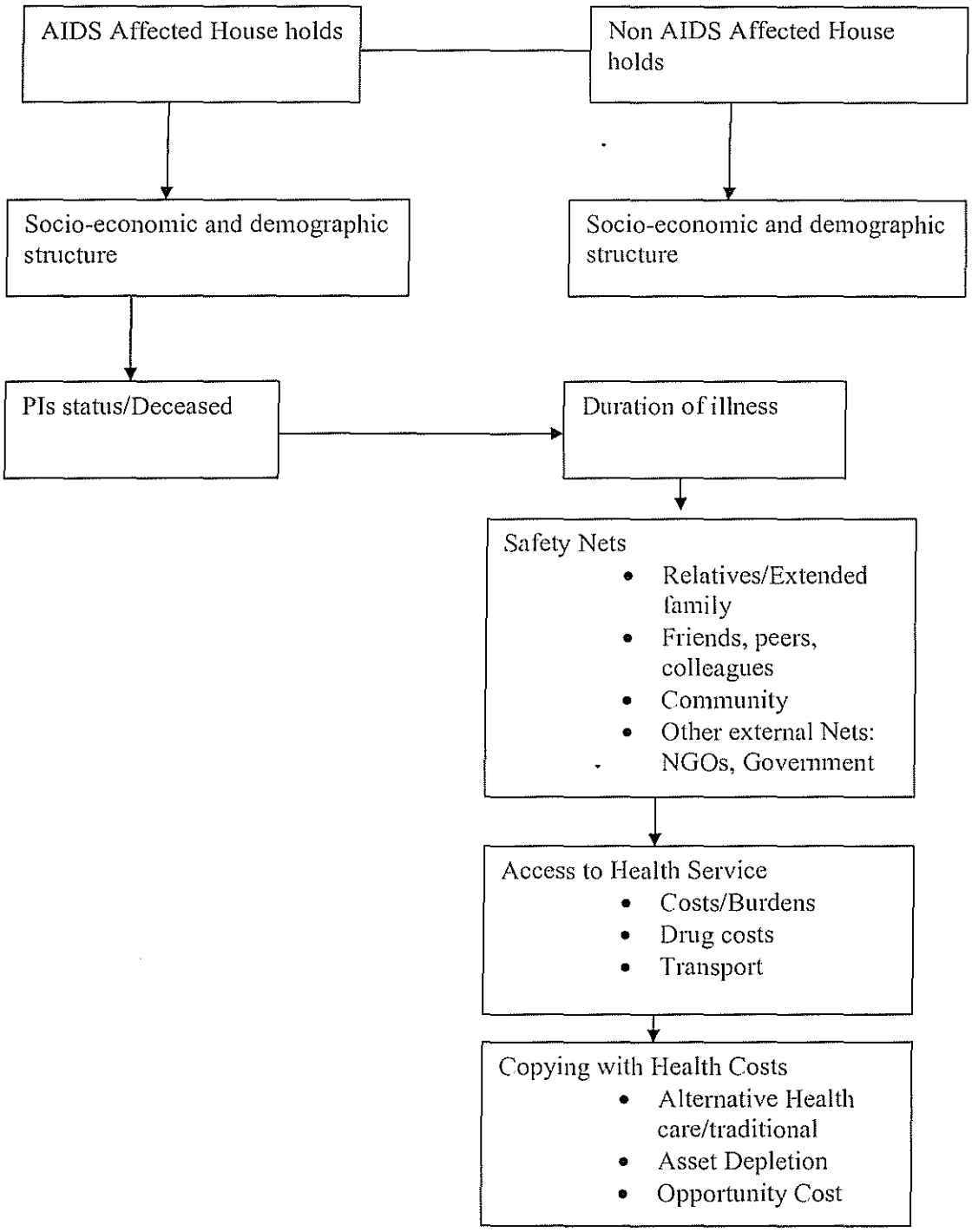


Figure 1 presents different scenarios of coping with user fees and other health care costs; the household or an individual may or might not have any safety net. Where the safety net exists, the affected can interact with it to access health services, and meet the associated costs. This will also be dependent on the ability and willingness of the safety net to assist the affected, which in turn will bear on coping mechanisms. In a scenario where a safety net does not exist, the affected will directly be confronted with the burden of health care costs which in turn will influence the coping mechanisms.

CHAPTER TWO
LITERATURE REVIEW

2.0 Introduction

This chapter reviews literature as an account of the knowledge and ideas that have been established by accredited scholars and experts in the field of study. It is guided by the objectives of the study outlined in chapter one. Since the introduction of user-fees in government hospitals and health centres several studies have been carried out to assess the general impact of the fees on health care utilisation (Asingwire et al, 1997; Barton and Bagenda, 1993; Wamai, 1993; Hansen, 1993). These studies and several others tackled the subject of the effect of user-fees on the general population, but not among AIDS affected households in rural Uganda. On the other hand, the early studies conducted on HIV/AIDS since 1986 when the government of Uganda adopted an open policy to the epidemic (Konde-Lule et. al., 1988; Ankrah et. al., 1988; Ndoleriire, 1993) exclusively focused on knowledge for HIV control and prevention. Other researchers (Kegeya-Kayondo et. al., (1990), Ankrah et. al., (1991) and Asingwire (1992) attempted to expose the epidemiological and sociological aspects of HIV/AIDS on the Ugandan population.

2.1 Social Life in the Community

A heterogeneous social life is led by the people in Nabukosi Sub-County inBugiri district based on what one does to earn a living. Along the roads, small commercial towns have developed which also serve as places for social meetings in the evenings for people in the surrounding localities. Beer is served in these daily clubs which will be open to all women and men, whether married or not. In addition, there will be weekly markets that operate on specific days of the week in various centres. The presence of the highways that cross the district implies increased business transaction among places and free movement of people to neighbouring Kenya and locally within and between districts.

2.2 Socio-economic Status

In general, rural areas of Nabukosi Sub-County in Bugiri can broadly be divided into three socio-economic categories; the rich, averagely well to do, and poor. The rich people in the community have a permanent house with iron roof, about five heads of cattle with an ox-plough, at least ten acres of land, and more than one wife/home, a radio, bicycle, hurricane lump, sewing

machine, sponge mattress and source of income is a wage employment or business in addition to agriculture.

The average well to do community members who live in houses which will be basically grass-thatched, having at least five acres of land, a few heads of cattle, goats and poultry, one wife/home and a bicycle. These constitute slightly a bigger proportion than the rich. The poor of the poor have a hut, with some poultry and less than one acre of land. These will be the majority, and who experience the wrath of HIV/AIDS. The specific socio-economic characteristics of the studied households will be summarised in Table 1.

Table 1: Socio-economic Characteristics of the Studied Households

Characteristics	Affected Household	Non-Affected Household
Headship		
Male	28.6% (10)	84.0% (21)
Female	65.7% (23)	16.0% (4)
Child	5.7% (2)	- -
Age of Members		
1 - 4 Years	12.2% (30)	11.4% (20)
5 - 9 Years	29.7% (73)	20.6% (36)
10-14 Years	41.6% (102)	21.7% (38)
15-20 Years	4.1% (10)	22.9% (40)
21 and Above	12.2% (30)	24.6% (43)
Occupation of Head		
Peasant Farmer	80.0% (28)	52.0% (13)
Salaried	5.7% (2)	12.0% (3)
Business/Commerce.	2.0% (5)	36.0% (9)
*MS of Head		
Married	31.4% (11)	80.0% (20)
Never Married	5.7% (2)	- -
Widowed	54.3% (19)	20.0% (5)
Separated	8.5% (3)	- -
H/Hold Type		
Nuclear	31.4% (11)	76.0% (19)
Extended	68.6% (24)	24.0% (6)

*Source :*Bugiri Hospital Records: 1999

From the Table above, sharp distinguishing features between AIDS affected and non affected households will be quite evident. The household composition reflects majority young population in AIDS affected as compared to non-affected. Headship of households affected by AIDS is female dominated compared to non-affected households. We find some cases of child headed households among the AIDS affected and none in non-AIDS affected households. Although in both scenarios, the occupation of household heads is peasantry farming, in AIDS affected households it is more pronounced as compared to non-affected. Whereas majority of household heads in non-affected will be married, we find majority household heads in AIDS affected widowed.

The affected households in the sample reported an average total monthly household income of shillings 15,062. The highest is shillings 60,000 and the lowest shillings 1,000. About 20% of the respondents interviewed had external sources in form of remittances from assets owned and located outside the home environment.

The non-affected households on the other hand, the average total monthly income is 54,461/=. The highest sample total monthly household income totalled to shs.100,000 while the lowest is shs. 3,000. The remittances for this category of households will be relatively higher as most of the owners will be men. One respondent will be a pensioner receiving shs.27,000 per month and also shs 3,000 per month from a lock-up.

2.3 The Local Economy

The economy of the people of Nabukosi Sub-County is based on agricultural production. Similar crops will be grown in the entire area with the significant differences showing in size of fields based on the wealth status of the farmer. The farmers in Ndifakulya County use ox-plough to cultivate. The rest of the counties use a hand hoe as the main type of technology in agricultural production. The mode of agricultural production is directly related to the size of the garden and the wealth of an individual. Maize, sorghum, millet, groundnuts, beans, sweet potatoes, will be found to be the major crops. There are also cash crops as cotton, the main cash crop before 1970s ceased production due to breakdown of the poor marketing system. The land tenure system in the entire area is uniform: freehold except in few cases of leasehold. Land acquisition is traditionally by father giving to the son. More land can be acquired through purchase. Majority of the families studied lived in homesteads consisting of at least round grass thatch huts with walls made from mud and wattle.

2.4 Communication in the Area

Like most parts of rural Uganda, rural Nabukosi Sub-County is not well served with sufficient communication network. Insufficient road network in rural Nabukosi Sub-County implies that motorised transport is not common, and hence people walk or ride long distances to Bugiri town and other towns in search of basic services, particularly health.

2.5 Traditional Institutions, Practices and Behaviours

The practice of indiscriminate sex behaviour is reportedly common in the study area despite the prevalence of HIV/AIDS. Beliefs in practices such as witchcraft being the cause of death gave the people a lee way to engage in sex with widows and widowers. A widow met in this study whom we shall call Anne (i.e not her real name) whose husband had died of AIDS narrated her experience as given in Case 1.

Whereas the above illustrates a case where impermanent and casual relationships evolve, cases of widow inheritance will be similarly reported. The Parish AIDS Committee Chairman in Kapyanga parish, for instance, commented that despite the extensive HIV/AIDS awareness campaign mounted by TASO in the area, people will be still cherishing traditional practices. Case 2 illustrates this point. One falling sick and gets abandoned by the would be helpers is reported to be a common phenomenon as in the above case. This, as it will be seen ahead adds to accessibility problems for AIDS patients to basic services such as health.

2.6 The impact of HIV/AIDS on household health care needs

One of the major objectives of this study is to document the various health are needs that accrue as a result of HIV/AIDS in the household. Although health are needs are ever present, it is conceptualised in this study that the on-set of HIV/AIDS in the household exacerbates the magnitude of the needs, while accessibility of health services becomes limited in the light of user-fees. In light of the foregoing observation, this Chapter focuses on what is found out to constitute health care needs in HIV/AIDS affected households.

2.6.1 Household Health Care needs

From both household and key informant interviews, there is acknowledgement among majority people from their experiences and information from TASO counsellors that AIDS patients take a fairly long time before they eventually die. Consequently, study participants expressed that due to prolonged illness, health are needs of AIDS-affected persons and their households will be enormous. Also observed by study participants is the fact that health care needs for an ordinary

patient who is not infected with HIV are of mild intensity as compared to a patient infected with HIV. That same situation is reflected at the household level.

2.6.2 Counselling Services

Psychosocial support in form of counselling will be echoed by household members of AIDS patients as a need which often AIDS patients suffer. The study found out that the PIs need counselling services so as to live a normal life. Those services will be provided for the purpose of inspiring the feeling of hope for life in the AIDS patients. A parish chief (key informant) in Buwunga County emphasised the importance of this need.

However, counselling, counselling services in Nabukosi Sub-County are not widespread. The AIDS Support Organisation (TASO) is the dominant NGO in the whole district which is providing this essential health service to the PIs. TASO has trained counsellors at parish level and has established Parish AIDS Committees (PACs) in the most AIDS-affected places in the district particularly Kapyanga, Muterere and Naluwerere parishes. The significance of such a move is to spread the services to the grassroots for the benefit of the PIs/PWHIV. Not only the TASO clients benefit but even the non-clients benefit. Clients are the AIDS patients tested, counselled and officially registered with TASO branch office in Bugiri.

2.6.3 Community Support

The PIs/PWHIV will need support from the community in form of sympathy, comfort and accepting to associate with them. Before the AIDS-awareness campaign is mounted by TASO counsellors and the clients, the AIDS patients are isolated, giving them a feeling of self-dejection and hate leading to emotional stress. However, this is still the case where the campaign will have intensive enough. A TASO client pointed out during the focus group discussion: "Some of my neighbours used not to allow their children to play with mine for fear that their children would be infected with AIDS."

Despite great strides undertaken to distigmatize AIDS, there still exists pockets of stigmatization in remote rural areas where AIDS campaigns have not taken much root.

2.6.4 Nutrition

Nutritional needs for AIDS affected households are reported by all study participants. Sporadically, famine has been ravaging areas in Eastern Uganda including Bugiri. The PIs/PWHIV as stated by the study respondents require special diet for better nutrition full of protein stuff. However, usual diet for the people in Bugiri is full of carbohydrates (millet,

sorghum, sweet potatoes and maize meal) except for sauce that is to say ground nuts and beans. The existing diet does not favour the conditions of AIDS patients as in one focus group discussion a PWA remarked in relation to his personal life: "Whenever I eat beans I develop a running stomach which costs a lot of money to stop as the drugs required are very expensive."

The study found out those attempts to provide the PIs with special diet is done mostly by the close relatives such as the brothers and sisters in the case of youth patients. The responsibility is enormous especially for those with little experience. The PIs who are older are supported by the married daughters, sons and relatives with the means. However, relying on external source is reported to be unreliable because at one period in time a person may be helping more than one PWA/PWHIV. In addition, the same person is faced with the burden of orphans and one's nuclear family and yet income is limited. In a focus group discussion with TASO clients at Bugiri hospital this is confirmed: "No one can provide every food you may wish to eat because people who assist us also have problems which require money, for example, my sister who has been assisting me with some money is also now infected by the AIDS virus and she complains of not having enough for their family as well."

Related with food provision, the distance between the people providing food assistance and the patient is found to be affecting its smooth flow. In all, the heavy burden arising from the health-care requirements of the PIs/PWHIV has driven the poor households to a situation of needy people. Particularly, the poor who are staying on their own and cannot produce food because they have been weakened by the frequent AIDS illnesses, face a more challenging nutrition need in that they have to provide themselves with food in order life to continue. Since the poor lack assets that can generate income, the problem is compounded when they fall sick of AIDS related illness victims. Case 3 summarizes such a scenario.

The sources of food in the area for HIV/AIDS patients are too limited. Apart from TASO no other NGOs or government department gives assistance to PIs/PWHIV. The food ratios provided by TASO to the clients are inadequate. The clients reported that they receive a monthly fixed ratio of five kilograms of maize floor, one kilogram of sugar and one litre of cooking oil. These food ratios are too inadequate especially to clients who are at the same time bread-winners to their families. Most of the participants in the study agreed that in face of the aforesaid situation, majority of the PIs/PWHIV derive money to improve their diet by selling their household items such as wall clocks, radio sets, dinning tables, cupboards, bicycles,

mattresses and beds if any. The next items considered for sale are assets that include land, houses, sewing machines, and livestock.

2.6.5 Nursing

Nursing of AIDS patients is mentioned as a serious need which patients face. Key informants in this study pointed out that nursing an AIDS patient involves spending resources. In a poverty ridden area such as Bugiri district, time is the most significant resource they lose in nursing. Both the directly affected households and those of the involved relatives experience a decline in their economic activities mainly agriculture and simple trade. The gardens remain unattended to, leading to a fall in output, income, and a threat to food security. Visiting the patients regularly is yet another need that has to be met. Frequent visits have the disadvantage of running down the little stock of food that may be available for the household consumption.

2.6.6 Sanitation and Hygiene

Proper sanitation and hygiene are expressed as needs for AIDS patients. Basing on the observation made in different households and areas of the district, people generally live in traditional houses (huts) located on well-drained sites. The challenge is to keep them clean regularly both inside and outside. The roofs are grass-thatched and need renewal annually in the rainy season. The courtyards have by routine to be swept every morning as the day's first activity. However, in some affected households, especially those headed by children and grand parents, sanitation and hygiene pose a lot of challenges. Patients in the terminal stages who are bed-ridden have to be taken care of in terms of sanitation and hygiene. These two constitute a serious need if the patient does not have a close person to look after him/her.

2.6.7 Medical Needs

The study participants will point out the AIDS-related illnesses are erratic and severe in nature. If PWA/PWHIV is to sustain his/her life it requires having some ready money for treatment. In case of any sudden illness he/she must immediately be taken to a health unit where at times one is confronted with the payment of user-fees.

2.7 Sources of Treatment in the Community

Several sources of treatment are available for the community. The government-aided and private health units, drug shops and medicinal herbs. The government-aided units include sub-dispensary at every sub-county in the district which are intended to provide simple treatment and

first aid. The dispensaries at county level are supposed to handle the more serious health problems including antenatal. Private clinics and drug shops scattered throughout the district provide treatment to many families in the district. The management is by trained medical staff particularly within the town. In a radius of about twenty kilometres outside town, there is almost no strict adherence on professionalism in the administration of the drugs. The non-government health units run by church organisations are Saint Henry Bugiri Hospital in Bugiri town.

The traditional healers located in various parts of the community are believed to be making a significant contribution in providing treatment to the sick members of the community. However, the effectiveness of the treatment given cannot be refuted or ascertained. Some individuals receive treatment from the two sources both modern and traditional. The study participants had a common view that obtaining traditional treatment is in most cases very expensive as it involved offering animal sacrifices.

2.8 Sources of Treatment for the AIDS-Affected Households

In this study, it will find out that the PIs/PWHIV mostly preferred government health units for treatment. The explanation given by the study participants is that government health units have since the colonial period been the main source of treatment for the majority of rural people and they have proved to be effective. Also, that the health services are among the services provided by the government from the funds collected from the taxes paid by the local people. In TASO's effort to help her clients particularly and other people suffering from AIDS, the existing health units are being oriented and utilised to meet the urgently required medical needs of the PIs/PWHIV. This has further encouraged the PIs to seek treatment from the government-aided health units. However, this call is not embraced due to lack of financial ability. One of the respondents, an AIDS patient interviewed expressed:

"It is a waste of time and energy to seek treatment from the government health unit when you have no cash. Treatment on credit is only possible when one is known to medical personnel at the unit. You would rather stay at home and wait for the last day of your life."

TASO branch manager at Bugiri reported an ambitious plan to orient health units in the district to effectively handle the PIs cases. This plan has partly been accomplished by retraining the existing staff of the health units and stocked the drugs that are mostly needed to treat the AIDS related-illnesses of the PIs/PWHIV. The ADRA, an Australian based NGO has already given some help.

A Mobile Clinic is established to reach people with AIDS who live far from the TASO-improved health units. The clinic is under the management of a medical doctor, two nurses and counsellors and expected to operate once in a month due to financial problems. Besides the government aided health units, the PIs/PWHIV also visits the health units that are used by the non-affected members of the community under emergency, which include private clinics, drug shops and traditional healers. An old woman whose 24-year old daughter has AIDS explained: "When my daughter suddenly falls sick and there is no money, I go to the forest and collect some herbs for her to get some temporary relief while we are looking for money to take her to the hospital. Sometimes, I purchase some drugs for say, shillings 200 to relieve pain." The old woman is emphasizing that government health units are the main source of treatment for the PWA/PWHIV. On the other hand, the non-affected members of the community find a better alternative outside the non-government health units.

CHAPTER THREE
METHODOLOGY

3.0 Introduction

This chapter presented the research methodology used by the researcher, which described the research designs, study or target population, sample techniques and sample size. It also included data collection methods, data analysis, ethical considerations and the limitations to the study.

3.1 Study Design

This study was carried out using a qualitative methodology. Thus, study areas were selected purposively on the basis of reported cases of HIV/AIDS. Similarly, qualitative methods of data collection were utilised.

3. 2 Population

Two households were selected; 25 AIDS-affected and 25 non-affected. The study did not aim at recruiting big samples, but rather manageable samples that generated an in-depth understanding of health care needs and coping mechanisms of both AIDS and non-AIDS affected households. A household was considered affected if it had a member with AIDS or had lost a member to AIDS, and finally if it had taken up relatives of the extended family such as children who had lost their parents/guardians to AIDS. On the other hand, a non-affected household had either not experienced any of the above, or the consequences of HIV/AIDS were not noticeable.

3.3Sample size and sample procedure

The sample size is a portion of the population whose results were generalized to the entire population under study. Ideally the whole population used to get information for research. However, it was not possible to investigate the whole population due to inadequate resources and time. A sample size was therefore deemed necessary. The immediate purpose of a sample was to increase the ability of generating the outcome of the population and to ensure that the sample includes all units of interest to the study.

3.4 Data collection instruments

Data was collected through household interviews, focus group discussions, in-depth interviews and observation techniques. Household Interviews. Data was collected on households as well as individual aspects including, among others, the status of the person with AIDS (PIs), i.e.

breadwinner versus dependants; economic status of the household; social status of the household including network of relatives, friends, and colleagues; nature of health costs; community attitude about costs of AIDS care and responsibility as opposed to other illness; and acceptance and denial of AIDS. To obtain the required data, the following qualitative data gathering techniques were adopted.

Focus Group Discussions. A total of sixteen focus group discussions were organized and conducted. Of these, 10 focus group discussions were held with heads of households (male and female). Others were: Adult males (2 LC 1 chairmen, an elder and 2 church leader); Adult females (2 LC 1 executive members, 1 council member and a teacher); Youths (girls); Female TASO clients; Parish chiefs of Buwunga sub-county; Parish AIDS Committee of Kapyanga.

In-depth Interviews. In-depth interviews were conducted with selected key informants. These included members of the health management committee ofBugiri dispensary, the in-charges and health staff of Bugiri and Osukuri health units located in Bugiri, West Buwunga and Bugiri counties, respectively. Other informants included Bugiri district Medical Officer and the Health Visitor, the Medical Superintendent and Senior Nursing Officer of Bugiri hospital, the sub-county chief, staff of TASO Bugiri branch, and the church leader at Naluwerere parish. Attempts were made during the interviews to assess key informants' exposure to HIV/AIDS on their own families. Their consent is enlisted in this regard.

3.5 Research procedure

The researcher obtained a letter from the Kampala International University to enable her visit the considered authorities in Nabukosi sub-county of Bugiri district to inform them formally about the forthcoming study. Key informants were purposively selected during the administering of the questionnaire. The research instruments used were designed to capture qualitative data. The questionnaires were administered to 25 respondents. The technique also enabled the researcher to learn new information relevant to the study, which had not been incorporated in the design of the instruments.

3.6 Data Processing and Analysis

All the focus group discussions and key informants interviews were tape-recorded, transcribed and processed in a Word Perfect software. Thereafter, the data was coded and analyzed using a

Hyper Research soft. Content and thematic analysis was adopted to bring out the impact of user-fees on equity of access to health services in AIDS affected household in rural Bugiri district.

3.7 Ethical Consideration

Only households that consented voluntarily participated. The consent was obtained from the head of the household and the primary respondent in case he/she is not the head. None of the participants is coerced to participate or incentives offered; monetary or material in exchange for information. The households in each category were identified by the Parish AIDS committee. Various stages in their illnesses were selected. The non-affected households were selected on the basis of at least one from each generation/household cycle: young, middle and old stages.

3.8 Limitations of the Study

i. Primary benchmark information was not easy to get from the respondent for reference. However, the researcher made use of the district documents and staff records.

ii. At the time of this study, it was like opening old wounds. The whole exercise raised emotions; some respondents were very rude and they even refused to give any information.

iii. This study was not an easy task. Being the first of its kind, the researcher faced a problem of getting relevant literature on the subject. Hence, it was difficult to get a strong basis for the research, and similar studies to compare findings with.

CHAPTER FOUR
PRESENTATION, ANALYSIS AND INTERPRETATION OF RESULTS

4.0 Introduction

This chapter of the study systematically presents the results that were obtained from the research that was conducted. The results are quantitatively and qualitatively presented. the analysis and interpretation follows tabular presentation at some stages and the interview results result from the respondents are also presented to supplement the presentation.

Tororo Hospital Health Management Committee endorsed in 1992 the introduction of the user-fees, making Bugiri hospital the first health unit in the district to implement the user-fee in Bugiri district. Three years later the scheme was adopted by the rest of the health units. The reasons given by the district authorities for adopting the user-fees was to find a solution to the inadequate supply of the essential drugs in the health units as well as an attempt to improve the staff welfare and overall standard of the health units in general.

The burden created by the user-fees to households in the community was of different magnitude, consequently leading to development of a variety of health seeking behaviours in the community.

4.1 Introduction of User-fees

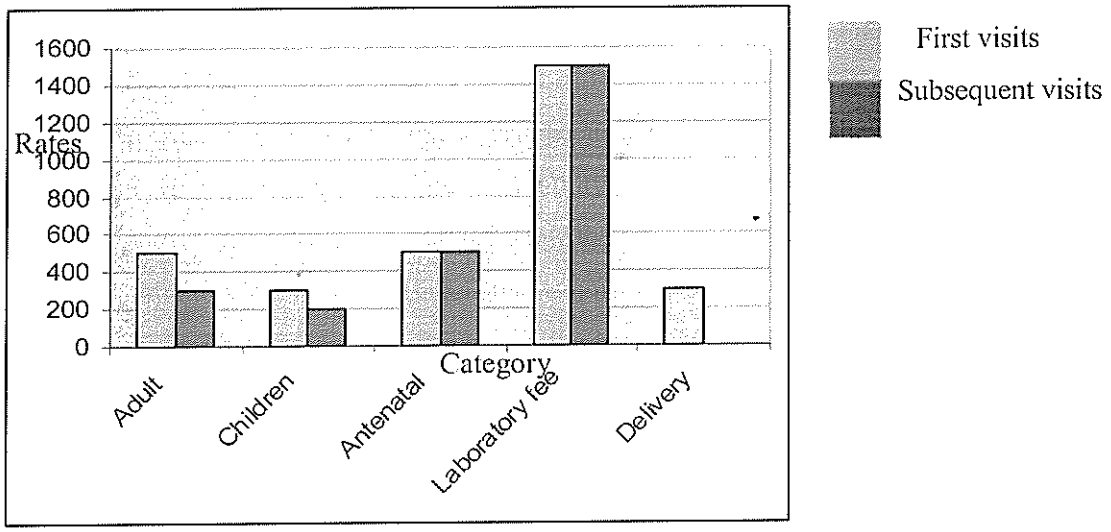
A top to bottom approach system was employed whereby the referral district hospital initiated, setting an example to the smaller health units below, that is dispensaries and sub-dispensaries, at county and sub-county levels respectively. The district leaders that is, Local Committees LC V Chairman, the Resident District Commissioner and the Chief Accountant first discussed the issue with Bugiri Hospital Management Committee who effected it in Bugiri referral hospital. Next, in collaboration, the leaders took the scheme to the lower health units in the rural areas. The political leaders mobilised those local leaders below them in organised seminars, while the District Medical Officer mobilised the staff in the rural health units under his office. The user-fee was formally introduced by each Health Unit Management Committee by submitting to the Local Council three executive proposals of the rates to be charged. On the approval of the user-fees rates by the Local Council three, the sub-county Health Management Committee sanctioned

the Unit Health Management Committee to affect the user-fee charges in their respective health units.

The original idea was for each area to fix the user-fees that suits the income of their local communities. Since the incomes of the community were equally skewed, the rates tended to be uniform as shown in Tables 3 and 4 which show the rates as approved and being implemented in the rural health units and in district hospital at Bugiri.

According to the District Medical officer and the health units' in-charge noted that the user-fee served a number of purposes. The user-fees collected were used for purchasing essential drugs as the routine essential drugs supply from the district was inadequate compared to the need. Part of the funds paid the wages of the staffs recruited into positions abolished by the government.

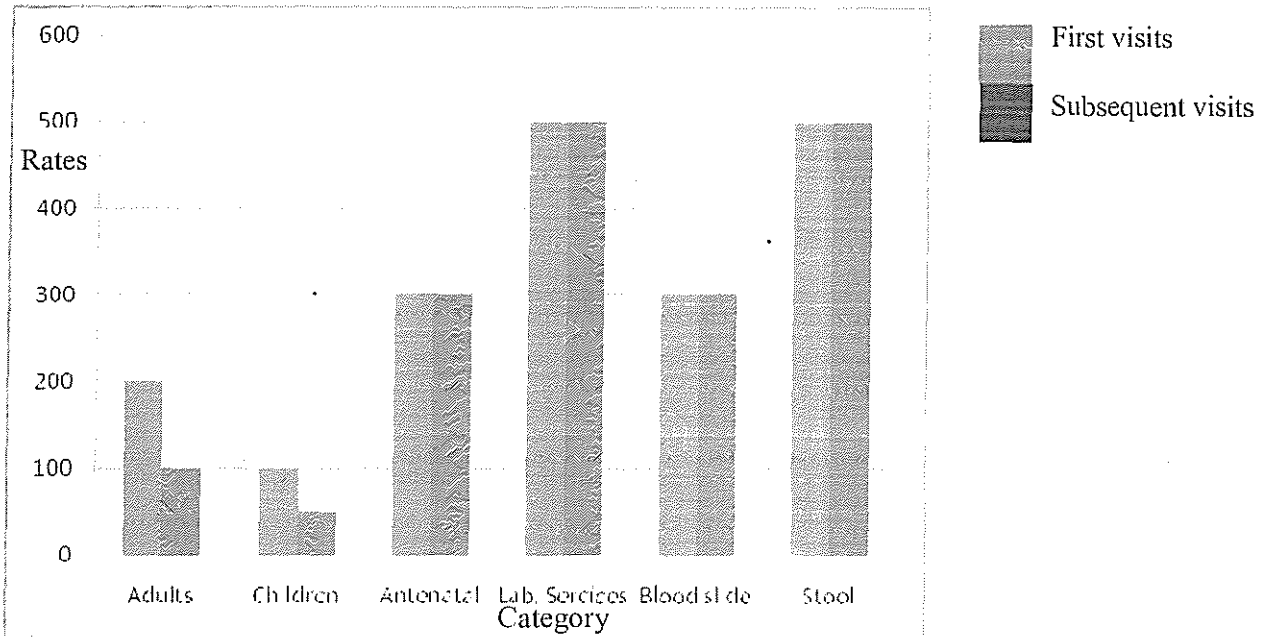
Figure 1: A grouped bar graph showing User-fee Rates charged at Sub-county Health Unit



Sources: Naluwerere sub-dispensary Records, 1995

Graph 1 show the user-fees which are charged at the sub-county Health Unit which are more equipped and provide more services than the sub-county Health Unit at sub-county level. The fees, although fixed by different independent health unit bodies as illustrated below: Adults at the first visit are charged 500/=, at the subsequent 300/=, Children are charged 300/= first visit and 200/= subsequent visit, Antenatal is charged 500/= at first visit, then at subsequent visit is charged 500/=, Laboratory fee at first visit is charged at 1500/= the at subsequent visit 1500/=, Delivery at first visit is charged a fee of 300/= then at subsequent visit is not charged.

Figure 2: A grouped bar graph 2: showing: User-fee Rates charged at Dispensaries



Source: Masafu Dispensary Records 1995.

Graph 2 shows the user-fees which are charged at the dispensaries which are more equipped and provide more services than the sub-dispensaries at sub-county level. The fees, although fixed by different independent health unit bodies as illustrated below: Adults at the first visit are charged 200/=, at the subsequent visit are charged 100/=, Children are charged 100/= first visit and 50/= subsequent visit, Antenatal is charged 300/= at first visit, then at subsequent is charged 300/=, Lab. services at first visit is charged at 500/= the at subsequent visit 500/=, Blood slide at first visit is charged a fee of 300/= then at subsequent visit is charged 300/=, Stool at first visit is charged a fee of 500/= then at subsequent visit 500/=. They have become uniform throughout the district. The hospital as expected provides more and a variety of health services in the district which are comparable only to those of the missionary hospitals in the district; St. Anthony Hospital in Bugiri Town and Bugiri Hospital near Busia Town.

4.2 Facilities for Treatment

In rural health units the free medical services that are provided include those medical services stated in the government national health objectives such as immunisation, First Aid, leprosy and Tuberculosis (TB). The other are exemptions as recommended by the local Unit and Sub-county Health Committees which are apparently uniform.

4.3 Exemptions

The exemptions as officially stated by the District Medical Officer, include children below one year, PWAs, members of LC executives, prisoners, medical staff, other political leaders, the poor and the needy, the aged, cases of mental illnesses, disabled, and victims of accidents.

The situation at Bugiri Hospital is not different. In this health facility the exemptions are approved by the Nursing Officers, Doctors and people approved by the LCs. However, all the members of the Health Management Committee and the top district and municipal officials together with their families are entitled to free treatment. But, the medical staff has an arrangement in which the cost of treatment for each member should not go beyond maximum value of Shs 15,000 per month. Exemption as an approach to enable persons with HIV/persons with (PWHIV/PWAs) access medical services amidst user-fee does not offer any relief to patients. The problem in particular is how to determine the PWA as all patients have to pay the user-fee until they have undergone the HIV test or full-blown signs are shown.

4.4 User-fee Rates for persons with HIV/persons with AIDS (PWHIV/PWAs)

Prior to testing, the patient is counselled. If found positive, PWAs/PWHIV is advised to join TASO where treatment is obtained either at Bugiri Hospital or from any of the sub-dispensaries supported by TASO where user-fees are equally charged to all patients seeking health services. Having had their tests done by the AIDS Information Centre (AIC) at Mbale, the persons with HIV (PWHIV) are encouraged to become TASO clients where they are issued with identification number for subsequent follow up. A part from Bugiri Hospital where the TASO branch is located, a number of health units in rural areas has been improved and the medical staff re-oriented to provide treatment to persons with HIV/persons with AIDS (PWHIV/ PWA). This is in addition to the counselling services the organisation offers.

The TASO Manager's statement implies that the persons with HIV/persons with AIDS (PWHIV/ PWA) like the non-affected are charged at the same rate of Shs 500 per visit. The size of the expenditure on health services depend on the frequencies of services sought. The PWAs with a high incidence of sickness therefore face a bigger health bill than the non-affected and hence, an enormous health burden. The assumption was that if community members had favourable attitudes about the money collected and were aware about the use the funds are put to, they would therefore willingly pay for the health services.

4.5 Knowledge and attitudes About User-Fees

The discussion on community's perceptions and attitudes is preceded by a brief examination of the implementation process of user-fees which inadvertently provide the context for people's attitudes. One of the issues of this study was to unravel community members' perception, knowledge and attitudes about user-fees for health services. The respective health unit staff in Bugiri implemented the user-fee in 1995. The Officers in-charge in the rural health units appoints the medical members of staff on rotational basis to collect the fees from both out-patients and in-patients. In the rural areas, monitoring is done by the Parish Councillors besides the other members of the Health Management Committee. At least two members; a female and male, on rotational basis daily visit the health units to ensure that only the approved fees are charged. They purportedly help the medical staff to identify the poor from their communities who cannot afford the charges but are in need of treatment. In Bugiri Hospital, the implementation was done in 1992 but not effectively due to management problems.

The problem that befell the implementation of user-fees influenced users' attitudes towards the whole policy. The user-fee implementation faced a number of problems. First, it all started on a very poor economic foundation in that the local community has weak financial capacity. The method of introducing user-fees was perceived by the community as being undemocratic and that it was intended to exploit the community for the benefits of those people in power, i.e. local council executives. What created more bitterness among the local people is the question of the purpose of taxation. They reasoned that since the main aim of levying tax is to enable government to provide such services as health, then the rationale for the user-fee introduction was not in good faith. In some areas user-fees introduction became an issue that was exploited by the local politicians. Indeed, in sub-counties with many activists, there was much resistance, when local politicians reminded the populace that even during the "buffoonery" regime of Idi Amin, government services were free, their scarcity notwithstanding.

In some units the problem was technical. The people assigned the job of fee collection were medical staff who did not have sufficient technical knowledge of book-keeping. This also interfered with their professional jobs. However, the people later trained to handle the accounts do not fall anywhere in the administrative hierarchy of the health unit. This causes an administrative problem. The other problem is the definition of who to exempt as far as the political leaders are concerned. Who in their families are covered, in-laws, friends? There was a feeling that even the small drug-kit received by the rural health unit is meant for treating those

already exempted from user-fee payment. These include Local council executives and their families, medical staff together with their family members including relatives and friends.

All in all, the local community expressed negative attitudes towards the user-fees. Participants in the study stressed that the prime limiting factor is lack of regular income. A successful user-fees implementation needs a reliable and regular income flow, which situation is quite contrary to what agricultural communities present.

There was no transparency and hence democracy when introducing user-fees in the health units. The community was not consulted to get their views whether they have the capacity to pay for those services or not. Information was held by the local council three executives. Very few respondents expressed that the user-fees collected by the health units were properly used. Both the affected and non-affected did not favour the idea of paying for health services unless the quality was improved. They similarly did not see the rationale of exempting management committees and staff, when paradoxically are the ones capable to pay.

According to the past experience about the corrupt behaviours of the medical staff, the respondents expressed doubt that the user-fee payment would be effective due to the under-the-table charges by the medical staff which habit was entrenched in 1970s. Another detrimental practice still persisting is where the health unit fails to provide the prescribed treatment from the health units and instead send the patients to purchase the drugs from pharmacies owned by the Unit staff. To the knowledge of the community, the drugs are being diverted from health centres to the private clinic and drug shops. Most of households interviewed believe that the user-fees are exorbitantly high. The community sources of income are so narrow and unreliable that they cannot sustain the frequency and prolonged sickness periods especially that of persons with HIV/persons with AIDS (PWAs/ PWHIV).

Majority of the respondents want the user-fees abolished as the whole mechanism has failed to solve the long standing issue of drug availability in health units. They instead introduced another burden of finance amidst the problem of the AIDS pandemic.

The user-fees as the study found out, are known to be benefiting mostly the health staff as shown by the proportion of the user-fee received. In practice, the staff has shown quick improvement in their attitude towards work. The community poses the question as to whether the government cannot find suitable alternative sources of finance to achieve the same objective i.e better welfare of the medical staff.

4.6 The Impact of User-Fee

The amount charged in form of user-fees as seen in Chapter Three was regarded as expensive due to two reasons cited by respondents. In the first instance, there were competing demands for the family against meagre resources. Second, majority people did not see the rationale of paying for health services in government units when they are already paying graduated tax. All in all, the introduction of the user-fee has impacted on rural households with regard to accessing health. We examine the impact on two types of households; AIDS affected and non-affected in the following sub-sections 4.7.1 and 4.7.2 respectively.

4.6.1 The Impact of the User-fees to the AIDS Affected Households

In this study, it was found out that the impact of AIDS on accessibility to health is unevenly distributed in households in both the affected and non-affected categories. The impact is gradually felt depending on the length of the period of illness of the person with AIDS/ persons with HIV (PWA/PWHIV). By the nature of AIDS related illnesses varying between three and eight years, the social and economic consequences to the households also vary. The above implies that it requires a regular and strong financial source in order to cope with the intermittent illnesses. The agricultural peasant nature of the economy cannot adequately support this kind of phenomenon. It was found out in this study, that to meet this need most households derive finance to support their patients from the sale of their property. The property that is first sold is furniture then livestock, and finally land as a man from Kapyanga parish whose daughter had died of AIDS in 1995. Even then, the income received is apportioned among the many needs that include household necessities and better nutrition. However, some PWAs who head households, due to limited income decide to look at the opportunity cost and sacrifice the money for their needs and instead spend it on household needs such as paying school fees, hiring more labour for agricultural production in order to have enough food for the family. The reasons advanced by such persons are that treating disease after disease which shows no sign of positive ending is a waste of resources. Such persons with AIDS (PWAs) therefore sacrifice their lives for the welfare of their families.

It was similarly found out that some persons with HIV (PWHIV) decide to spend all the available financial resources only on the required nutrition at the expense of other health needs such as medical. However in some cases, the reverse is true, person with AIDS/ persons with HIV (PWAs/PHIV) living far from health units but not able to meet transport costs and the required medical fees, they just refrain from seeking treatment and stay at home waiting for any

consequences. Joining new churches in hope that AIDS can be cured spiritually was found to be an impact of AIDS as well as a way of coping with the disease. So unable to afford the user-fees, persons with HIV/persons with AIDS (PWHIV/PWAs) out of despair join these churches hoping to get cured from getting saved from own sins. The effectiveness of this kind of treatment is yet to be proved. Also, unable to meet the costs of treating AIDS-related illnesses, person with AIDS/ persons with HIV (PWAs/PWHIV) for long remain bed-ridden; creating an atmosphere of perpetual unhappiness in their families. Members of the households especially the children become traumatized by the hospital kind of atmosphere and despair about the apparent results of the death of their family member.

4.6.2 The Impact of User-fee on Non-Affected Households

Although the non-affected households also feel the impact of user-fee in accessing health services, it was not found to be as severe as in AIDS affected households. The cost burden of accessing health care in form of transport, under-table payments and or, buying drugs impose a heavy burden among the non-affected households. The difference between the two types of households is that non-affected can easily cope with the situation compared to households ravaged by AIDS. Some households, however, first sell some property to meet the various health costs but the sell involves property of relatively less value, such as a chicken. Others would save the property but get the money from working in the fields of the wealth farmers in the village. Under the situation of sickness the money is taken in advance of work.

4.7 General Accessibility to Health Services

The most significant obstacle to obtaining treatment as reported by study participants is financial. The local economy in the rural areas of Nabukosi Sub-county ofBugiri district is based on agricultural activities. The main income source is from the sale of crops such as millet, maize, sorghum, and ground nuts. These crops are also the main food crops. Their production is limited to an average of less than one acre. Crop production has since 1980s been affected by progressive weather changes and famine frequency on the increase. Cotton the main cash crop was abandoned due to lack of incentives to the farmers. On the other hand, management of livestock has been poor due to absence of veterinary extension services and farmers' education. All this is compounded by the fact that often the treatment prescribed at the health unit cannot be provided due to lack of drugs. Instead the patient is required to purchase the drugs from a specific pharmacy.

The shortage of drugs is due to a number of factors. The community believes that the drugs are diverted by the medical staff to their private clinics usually situated close to the health units, while the in-charges deplore the meagreness of the fees collected, and hence not enough funds are left to purchase the drugs after deducting the 50% for staff welfare and other expenses as already observed. Under the user-fee there is a provision for treating on credit. However, this provision has not benefited many because there is no stipulated method of recovering the debt. Besides, the provision is not publicly known for fear by the implementers that even those who are able to pay might ask for a credit.

Generally, the impact of user-fee has been felt into two stages. When the user-fees were introduced in 1992 inBugiri hospital, the community then sought health services in the rural health units. This created shortages of drugs. Consequently, like in the main hospital atBugiri, the health units decided to introduce the user-fees in 1995 to mobilise funds to purchase more essential drugs to meet their rapidly growing demands. The study participants stressed that the community confronted with the problem of the user-fees, members had to choose among the alternative sources of treatment whenever one fell sick. A number of households have responded to local herbs, drug shops and private clinics. The health situation in the community is likely to worsen given also the factors that constrain the community from seeking and obtaining treatment.

4.8 The Copying Mechanisms of the Non-Affected Households

The study participants reported that individual households headed by the young and middle aged are in a better position to effectively cope with the health care costs. Several means have been adopted. One such mechanism has been to expand the acreage under each crop by using more labour through mobilising the peers, members of the households working for extra hours, acquiring extra land to cultivate, crop diversification, adopting a more yielding cash crop such as rice. These strategies have proved to have achieved increased output and hence increased incomes for individual households. Agricultural production, however, is subject to weather vagaries, health and household composition in addition to the size of the market for the output.

Some, particularly the mature households hire out their labour at weeding. How much one works depends on the needs to be achieved. The people who regularly work for some progressive farmers have the advantage of getting money in advance to go and settle health bills, then work later to cover the money obtained. In this study, it was found out that some youths

from non-effected households start small-scale businesses in trade, brick-making, repairing electronic gadgets but these are limited by the size of the market and the low income of the community.

4.9 The Copying Mechanisms of the Affected Households

The affected households face more health care costs and burdens as indicated in Chapter Four. The copying mechanisms they have devised have been at individual, household and community levels.

4.9.1 Copying Mechanisms of Individuals

The study found out that individuals had different methods of copying with HIV/AIDS. Both young men and women tended to take refuge in the church under the guise of having received salvation.

Evidently, a number of churches for the born again were observed in the area and all the guides in the field were saved people. Some young men after the death of a partner, however, handle the health care needs such as medical expenses, nutrition requirements by generating money from commercial activities. Case study 4 of Mabonga illustrates this mechanism.

The study also reveals that some person with AIDS/ Persons with HIV (PWA/PHIV) cope with the stress by seeking counselling services and medical services for the illnesses. In some cases men after losing their wives adopt the extreme behaviour and take refuge in bars and increase alcoholic in-take. Women on the other hand, overwhelmed by the burden of the size of the family, remain in their late husbands' homes. The asset viewed as most important given their circumstance is land on which to produce food to feed the family.

4.9.2 Copying Mechanisms by Individual Households

The study findings reveal that when the active members of the labour force in the household dies or becomes weak as a result of AIDS related illness, there is a tendency to devise ways of supporting the family basing on the existing family labour force. Older children especially below the age of 18, tend to be withdrawn from school to take up income-generating activities in order to provide the health needs of the patient and that of the household as a whole. Case 5 summarizes such a scenario. The boys are conditionally forced into early marriages to produce food and generally give support to the parent's household.

Households which find it difficult to manage due to poor economic conditions, the burden of looking after the orphans is shared among the relatives who have the financial capacity to assist. In some cases, the children remain in the home staying with some adults while receiving assistance from the relatives. Such assistance is unreliable and is withering away as all families become affected. The study further found out that it is a burden for the PWAs to access health services. The common means of transport is bicycle which due to the poor health conditions, some PWAs cannot manage to use. To cope with this problem, the relatives of the PWAs use stretchers, beds or arm-chairs mounted on a bicycle which they use for ferrying the patients to the health units. The non-affected households, on the other hand use the most common convenient means of travel which is own or hired bicycles and sometimes on foot or by public vehicles as they can afford.

4.9.3 Community Support to AIDS Affected Households

Local communities in the district have not actively responded to the problems of AIDS. The effort to assist the affected households and patients is from outside the district. A local organisation, called Remajo, so far consisting of the non-AIDS patients, combining youths and women was set up in Kirewa sub-county to sensitise the community on the HIV/AIDS in the rural areas.

The person with AIDS/ persons with HIV (PWAs/PWHIV) have been organised under TASO to increase their capacity to individually meet the health-care needs. A club has been established at the branch headquarters for making pieces of craft material for sale. Besides this activity, the group has launched an AIDS-awareness campaign to win community support which is one of the health needs, so that the community changes their discriminative attitude towards them as AIDS patients. The strategy used here is staging drama shows supported by TASO and intended to depict to the members of the community that even the AIDS patients are integral members of the society and deserve humane treatment.

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CHAPTER FIVE

SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.0 Introduction

This research presented the summary of the findings, conclusions and recommendation. The research dealt with the impact of user-fees on equity of access to health services in AIDS affected households in rural Uganda a case study of Kapyanga Sub-County in Bugiri district. In this chapter, the researcher gives a summary, draws conclusions and lastly makes recommendation of the research.

5.1 Summary of findings

In chapter one, the researcher gives a clear situation that prompted her to go in for this research. In the background of the study, the researcher puts forward a question that prompted her to carry out the study that is; How do user-fees impact on seeking behavior of HIV/AIDS affected households in rural Uganda Nabukosi Sub-County in Bugiri district

5.1.1 The Impact of the User-fees to the AIDS Affected Households

In this study, it was found out that the impact of AIDS on accessibility to health is unevenly distributed in households in both the affected and non-affected categories. The impact is gradually felt depending on the length of the period of illness of the person with AIDS/ persons with HIV (PWA/PWHIV). By the nature of AIDS related illnesses varying between three and eight years, the social and economic consequences to the households also vary.

5.1.2 The Impact of User-fee on Non-Affected Households

Although the non-affected households also feel the impact of user-fee in accessing health services, it was not found to be as severe as in AIDS affected households. The cost burden of accessing health care in form of transport, under-table payments and or, buying drugs impose a heavy burden among the non-affected households. The difference between the two types of households is that non-affected can easily cope with the situation compared to households ravaged by AIDS.

5.1.3 General Accessibility to Health Services

The most significant obstacle to obtaining treatment as reported by study participants is financial. The local economy in the rural Bugiri is based on agricultural activities. The main

income source is from the sale of crops such as millet, maize, sorghum, and ground nuts. These crops are also the main food crops. Generally, the impact of user-fee has been felt into two stages. When the user-fees were introduced in 1992 in Bugiri hospital, the community then sought health services in the rural health units. This created shortages of drugs. Consequently, like in the main hospital at Bugiri, the health units decided to introduce the user-fees in 1995 to mobilise funds to purchase more essential drugs to meet their rapidly growing demands. The study participants stressed that the community confronted with the problem of the user-fees, members had to choose among the alternative sources of treatment whenever one fell sick. A number of households have responded to local herbs, drug shops and private clinics.

The health situation in the community is likely to worsen given also the factors that constrain the community from seeking and obtaining treatment.

5.2 Conclusion

After a thorough and comprehensive study of the entire research report, the researcher came up with the following conclusions, which were based on research findings and literature review. The study findings indicate that majority of people agree to pay for health services. They recognize, among other things, the importance of quality services. However, the majority admit having to make tremendous sacrifices in order to meet health costs. In fact, the utilization of health services represents rather a last resort, once the person is really ill and has no other solutions. Several users mentioned having to sell personal belongings or do without some of them to meet the costs. Key informants acknowledged that the populations have had to borrow from relatives, friends, or acquaintances" to meet the medical costs. They were also aware that many people sacrificed other basic necessities to access health care. Indebtedness and privation are thus part of the solutions that users consider when having to pay for health services.

In general, where the government has not officially supported the Bamako Initiative policy but where cost recovery mechanisms are progressively taking form, the population seems to be caught unawares regarding these new liabilities. The people interviewed clearly recognize the negative impact that user fees can have. The affordability of health services is very quickly compared with all the other liabilities and what little income the majority of households earn. Moreover, people tend to use the services of traditional healers very little. Traditional medicine is not an alternative that people choose.

Finally, i wish to reiterate that user fees implementation process aiming as a priority at an improved availability of services through the revitalization of PHC and a redistribution of the generated income to ensure greater accessibility to services for the most disadvantaged are the prerequisites for the successful implementation of cost recovery mechanisms.

5.3 Recommendations

Income Support

Majority needs of HIV/AIDS affected families' spring from lack of income which dwindles as a result of prolonged sickness or was already meagre prior to on-set of HIV/AIDS in the household. Thus, interventions aimed at assisting PWAs and members of their immediate families ought to focus on poverty alleviation as a central issue. For, even if health services were to be freely accessed, there are other costs that must be incurred before accessing the services such as transport and even for drugs that might not be available at the public health centre. There are other needs which AIDS affected families experience, and if not attended worsen the health situation of the infected member such as nutritious food stuff. To address this problem, simple and manageable income generating activities for HIV/AIDS affected families could be a step towards supporting such families. Caution must, however, be made that supporting IGAs especially for HIV/AIDS affected families can be complicated and hence need to be thoroughly analysed especially with regard to the nature of activities. This can still be plausible if the affected member of the family has not yet developed full blown AIDS. Otherwise, in such a scenario remedial care would be an alternative i.e., provision of in-kind and cash benefits than support to IGAs.

Exemption Mechanisms

It has been observed in the study that AIDS patients are in theory exempted from paying user-fees, but in practice, the implementation of this mechanism is rather fraud. The identification of patients to be exempted leaves room for abuse, and in any case not all AIDS patients come out in the open. But also exemption might not have significant impact if the AIDS patient were the breadwinner to the family. It is a considered recommendation that in situations where an AIDS patient happens to be the breadwinner, his/her dependants should also be covered by the exemption mechanism, its performance and effectiveness notwithstanding.

Quality of Service

The community resistance towards paying user-fees is partly attributed to low quality services that are received in turn. Reports were received about community members who opt for private providers especially missionary founded hospitals where they pay a bit higher, but get the services. Thus by launching user-fees in public health centres and units before equipping the units is not an attractive way of getting health users pay for the user-fees. It would possibly be helpful if health centres were equipped before introducing user-fees.

Information Dissemination

As noted in the text, the introduction of user-fees caught health users unawares. This led to questioning the rationale of paying for health services when people were already paying taxes. The implication is that no policy will work well if information about it is not disseminated to people that will be affected by the policy in question. All those involved in implementation.

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APPENDIX I

Household and individual questionnaire

The impact of user-fes on equity of access to health services in aids affected households.

the case of Nabukosi

Sub-countytororo district household identification

1. Gender

Male ☐ Female ☐

2. Marital status

Single ☐

Married

Separated ☐

Other specify ☐

3. Age of the respondents

20-25 ☐

26-30 ☐

31-35 ☐

36-40 ☐

41-50 ☐

50 ☐

4. Highest level of qualification (*Please tick one)*

Less than bachelor ☐

Bachelor ☐

Graduate ☐

Any other specify.....

5. Relation to Head of household

Head ☐

Spouse ☐

Child Accountant ☐

Relative

Any other specify.....

SECTION I: SOCIO-ECONOMIC STATUS OF THE HOUSEHOLD

6.Make a description of the economic conditions of the household; physical appearance, size, types of assets, cleanliness etc.....

.....

7.Who is the main income earner/breadwinner for the household?.....

.....

8.What is his/her main economic activity?.....

.....

9.What are other supportive economic activities?.....

.....

10.Who are the other earning members? What are their economic activities?

.....

11.What is the approximate weekly/monthly household income?.....

.....

12.Are there other sources of income to the household (e.g. rent, remittances from external sources, home based production activity).....

.....

SECTION II: HOUSEHOLD EXPERIENCE OF HIV/AIDS

13. Is there a member in this family who has AIDS related illness? Who is this? (i.e. Head of the household/breadwinner, child, spouse).....

.....

14. Have you ever lost a family member of AIDS related illness? Who is this? (i.e Head of the household/breadwinner, child, spouse).....

.....

15. Are there relatives to this family who had/have AIDS related illnesses?

.....

16. How have their sickness/death affected this household?

- Financial Burden
- Extra responsibilities of taking on siblings
- Time Consumption

SECTION III: IMPACT ON FINANCIAL CONDITION

17. Has the problem of HIV affected the economic situation of the family? If yes, how? and how much? (living standard has come down, school drop out, gardens unattended, property

sold).....

.....

18. Has any additional member(s) had to take up earning responsibility? Who?

.....

19. Has the family had to take financial help from other sources? If yes, which are these?

.....

.....

20. If not, do you anticipate financial need in the immediate future? Whom do you expect to contact for it? Is assistance expected/required from an external agency (like NGO, Government)?

.....

SECTION IV: SUPPORT AND CARE IN THE AFFLICTED HOUSEHOLDS

21. What kind of support/care does he/she need currently? For how long has he/she been sick?.....

.....

22 Who is providing support/care or who is expected to provide that care?

.....

23. If physical care is needed, describe the kind of care (e.g. if bedridden, needs support for standing/walking, for bathing etc). Who is (are) providing this care? Is the need for

SECTION VI: HOUSEHOLD SOCIAL SUPPORT NETWORK

30. Who from among these is perceived as a source of support to the family in times of need (not only for HIV), emotional, financial, material.....

.....

31. Is support being sought from any of these members in the current situation?

.....

32. If yes, what kind of support is being sought/given. If no, why not?

.....

33. Do you feel the position/status of the family is being compromised when seeking resources from these members?

.....

34. Which are institutional supports for the family? (self help group, community welfare group, religious organisation, peer group.

etc).....

.....

35. Are you a member of any of the above organisations?

.....

36. Do you seek support/help from that group when in need? Generally what type of need? Have you sought help in your current situation-if yes, what help; If no-why not? do you plan to seek help in

future?.....

.....

37. In overall terms, do you feel you have an adequate social support network in this village to fall back upon in times of need/crises?

.....

SECTION VII: HEALTH SEEKING BEHAVIOUR AND THE IMPACT OF USER-FEES

38. Where do you and members of this household normally seek treatment when sick? (Health centre, Hospital, Traditional practitioners, self-

39. medication).....

.....

39. What means of transport do you use to this source?

.....

40. What problems are involved in travelling to this (i.e. in terms of transport costs) source?

.....

.....

[For Health Centres/Hospital Users]

41. Do you have to pay for the services at the health centre? What payments have to be made?

.....

42. Are there some services that you have to pay now that you did not pay for before? Which ones?

.....

43. How would you rate the fee you pay for treatment (fair, expensive).....

.....

44. If you can't pay for the services, can you have access to the services at the health centre?

.....

.....

45. Are you offered different payment alternatives (e.g. in several instalments, non-monetary etc).....

.....

46. If services at the health centre are unaffordable, where do you seek health services?

.....

SECTION VIII: EQUITY OF ACCESS

47. Who is responsible for the health or for the health care needs of family members?

.....

48. Who decides where family members should seek health services?

.....

49. Did you ever have to sell property or give goods to pay for medical expenses? If so, what kind?

.....

50. Do you (and your family) usually use the services whenever you fell like using them?

.....

.....

51. How much do you pay each time that you use them?

.....

52. How much money did your family spend on health care during the last 3 months? Is this affordable?.....

.....

SECTION IX: ATTITUDES TOWARDS USER-FEES

Now I would like to read a few statements to you, for which I request you to answer "Yes", "No" or "Don't know".

	Statement	Yes=1	No=2	DK =3
54.	User-fees are exorbitantly high			
55.	User fees should be abolished			
56.	User-fees are misappropriated			
57.	User-fees are beneficial to the health centre			
58.	User-fees should be paid by a few			
59.	User-fees head to improved services			
60.	User-fees lead to increased drugs			
61.	User-fees promote the welfare of the health staff			

APPENDIX II

INTERVIEW GUIDE FOR THE KEY INFORMANTS

THE IMPACT OF USER-FEES ON EQUITY OF ACCESS TO HEALTH SERVICES IN AIDS AFFECTED HOUSEHOLDS IN RURAL UGANDA:

THE CASE OFBugiri district

Designation: .....

Sex : .....

1. How are user fees introduced and how are they implemented?

.....

2. Are there some services that are offered free of charge? If so, which ones?

.....

3. Who decides between paying services and free services?

.....

4. Is the money that the health centres receives through user fees reinvested in the health area and more particularly in the health centres?

.....

5. Do you think there have been improved services since the implementation of user fees? Explain.....

.....

6. Do people seem happy about the quality of services? Explain.....

.....

7. What are the advantages and disadvantages of the implementation of user fees?

.....

.....

8. How big is the HIV/AIDS problem in this community?

.....

9. Have you had any of your family members/relatives with HIV/AIDS? Who is this?

.....

.....

10. What has been the impact of HIV/AIDS on you/your family?

.....

11. Do community members with HIV/AIDS and their families pay for health services? If no, what are the exemption mechanisms?

.....

12. What is the policy for people who seek for health services but cannot pay?

.....

.....

13. What other problems do you think people with HIV/AIDS and their families face?

.....

.....

14. How do they cope with these problems?

.....

15. What is community role in supporting PIs and their families?

.....